

HB 5212
R. Hoyt

I'm 51 years old with Severe Hemophilia A with an Inhibitor to Factor VIII. An inhibitor is an antibody that my body developed that rejects the medication to treat my hemophilia. I was one of the first diagnosed with an inhibitor in the state of CT back in the early 70s.

As a young boy I had to learn how to manage this disease without any clotting factor for the first 33 years of my life. It's a miracle that I'm still alive and walking. I'm sorry that I can not be with you today as I'm on an important mission that was scheduled months ago.

Twelve years ago I was working for a company that offered medical insurance that did not allow me to go out of network for my Hemophilia needs. I was given names of doctors that were in the area that could treat my Hemophilia needs. None of them had any experience in treating someone with hemophilia but I choose one to be covered if any thing ever happened.

As a child I was brought up in an environment that had many safety barriers that were put in place by my parents, teachers and medical teams to prevent any undo harm to me. By the grace of God and lot of prayers things went quite well.

But in 1998 things went terribly wrong at the age of 40 when the Doctor that was treating me could not get a hip bleed under control. I found out later that I was not getting the full dose because the insurance company would not pay for the required amount. For the first time in many years I was hospitalized to do round the clock clotting treatments. After a few days in the hospital and many treatments I had a heart attack due to an over dose of clotting factor. It was obvious that they did not understand the severity of my disease and now I suffer because there were no real guidelines for my needs and well being.

The problem started when the insurance company denied any out of network services for my special needs. The second problem was I had a doctor that was not familiar with the needs and care of hemophiliacs. The third problem was that I was forced to use a clotting product that did me more harm than good. All because the insurance company wanted to cut corners or maybe someone that was calling the shots was unqualified and ignorant of my real needs. I now have a fifty percent loss of heart function. I believe that if the insurance company did not have the power to dictate the clotting factor they wanted to use (the cheaper one) I would not be in the situation I'm in today. I also believe that if I had access to a Hemophilia Treatment Center (HTC) I would not have experienced the heart attack.

Since this horrible episode, I now see doctors that specialize in Hemophilia and go to one of the HTCs in CT and it's has been a wonderful experience. Now I receive services and products that allow me to have a quality of life I have not had in many years.

Please pass this important bill before someone else is denied the proper services and products that are needed to prevent disasters like mine.

Thank You
Robert Hoyt